Palliative care in long-term care facilities: a European perspective

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2019

document version
Publisher's PDF, also known as Version of record

Chapter 5

Palliative care provision in long-term care facilities differs across Europe: results of a cross-sectional study in 6 European countries (PACE)

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Published in Palliative Medicine. 2019;33(9):1176-1188.

Abstract

Background: While the need for palliative care in long-term care facilities is growing, it is unknown whether palliative care in this setting is sufficiently developed.

Aim: To describe and compare in six European countries palliative care provision in long-term care facilities and to assess associations between patient, facility and advance care planning factors and receipt and timing of palliative care.

Design: Cross-sectional after-death survey regarding care provided to long-term care residents in Belgium, England, Finland, Italy, the Netherlands and Poland. Generalized Estimating Equations were used for analyses.

Setting/participants: Nurse/care assistant most involved in care for the resident.

Results: We included 1298 residents in 300 facilities, of whom a majority received palliative care in most countries (EN 72.6%-BE 77.9%), except in Poland (14.0%) and Italy (32.1%). Palliative care typically started within 2 weeks before death and was often provided by the treating physician (EN 75%-NL 98.8%). A palliative care specialist was frequently involved in Belgium and Poland (57.1% and 86.7%). Residents with cancer, dementia or a contact person in their record more often received palliative care and it started earlier for residents with whom the nurse had spoken about treatments or the preferred course of care at the end of life.

Conclusions: The late initiation of palliative care (especially when advance care planning is lacking) and palliative care for residents without cancer, dementia or closely involved relatives deserve attention in all countries. Diversity in palliative care organization might be related to different levels of its development.

Introduction

The need for palliative care in long-term care facilities in Europe is growing. More people reach older age[1, 2] and for some admission to a long-term care facility is unavoidable due to their complex care needs.[3-5] Palliative care is essential in these facilities, since most residents will stay there until death.[3] Researching palliative care provision in long-term care can give a notion of how well palliative care is developed and whether it meets the growing need. While country informants have crudely estimated the level of palliative care engagement in long-term care facilities,[6] representative and comparative research of palliative care practices in long-term care facilities in Europe is lacking.

Evidence of factors related to palliative care provision and timing of initiating palliative care, can provide further understanding of palliative care development in European long-term care facilities. Such research is scarce, however studies in other populations found associations with advance care planning (ACP), resident and facility characteristics. For instance, in U.S. nursing homes and hospitals use of palliative care increased when patients engaged in ACP.[7, 8] Furthermore in general practice in Belgium, Italy, the Netherlands and Spain, patients with cancer were more likely to receive palliative care[9-12] and to be referred earlier to specialist palliative care.[11] Country differences were evident, for example, older patients' odds of receiving specialist palliative care were higher in Belgium[9, 11] but lower in Spain and Italy.[9] Swedish nursing home managers considered lack of qualified nurses a barrier for providing palliative care.[13] A Delphi study identified factors to ensure palliative care provision for patients, which included guidelines regarding palliative care, case managers for patients in need of palliative care and organizing multidisciplinary meetings.[14]

This study aimed to describe and compare current palliative care provision in long-term care facilities in European countries, which can support and inform future palliative care development in this setting. To this end the following research questions are addressed in this paper:
1) what proportion of long-term care residents received palliative care; how long before death was palliative care initiated; who was involved in providing palliative care for these residents; and are there differences between European countries?
2) which resident, facility and advance care planning factors are related to whether or not older people in European long-term care facilities received palliative care?
3) which resident, facility and advance care planning factors are related to the timing of initiating palliative care for older people in long-term care facilities in Europe?

Methods

Study design

This study used data obtained between January 2015 to December 2015 in the "Palliative Care for Older People" (PACE) project, which included a cross-sectional study of deceased residents of long-term care facilities in Belgium, England, Finland, Italy, the Netherlands and Poland.[15]

Proportional stratified random sampling obtained representative samples of facilities in each country, accounting for region, facility type and bed capacity. As in Italy a public list of facilities was unavailable, a convenience sample was based on a previously constructed cluster of long-term care facilities, covering the three macro regional areas and accounting for the sizes and facility types in Italy.[16]

Facilities reported all deaths of residents in the preceding 3 months. Concerning each deceased resident, structured questionnaires were sent to the facility administrator/manager and the staff member (nurse or care assistant) most involved in care. The administrator/manager also filled out a questionnaire on facility characteristics.

Ethical approval was obtained in each participating country. With the exception of Italy and the Netherlands, where ethical committees were informed but ethical approval wasn't needed for the use of retrospective data of deceased residents. Returning a questionnaire was regarded as consent to participate in the study.

Sample

A total of 322 facilities participated in the PACE project. In these facilities 1707 deceased residents were identified, these included all residents who died in the 3 months prior participation. For 1696 residents (99.4%) the staff member most involved in care was identified and they returned questionnaires regarding 1384 residents (81.1%). This study selected 1298 residents (76%) (in 300 facilities) with a valid answer on the question "According to you, did the resident receive palliative care at any time?".

Measurements

Aspects of palliative care provision, indicated by care staff, were dependent variables in analyses (see table 1). A definition of palliative care was not provided in the questionnaire. Resident and facility characteristics and indicators of advance care planning were independent variables (see table 2).

Table 1. Aspects of palliative care provision included as dependent variables

Variable	Question	Answer categories	Respondent
Resident received palliative care	According to you, did the resident receive palliative care at any time?	-Yes -No	Care staff
If the resident received palliative care, the following questions were answered:			
Timing of initiating palliative care	How long before death was palliative care started?	-Number of days	Care staff
Treating physician [a] provided palliative care	According to you, did the treating physician provide palliative care to this resident?	-Yes, until death* -Yes, not until death* -No	Care staff
Palliative care specialist involved in providing palliative care	Which of the following persons or organisations were involved in the provision of palliative care for the resident?	Country specific answer categories[b], recoded into: -Yes (palliative care specialist could be: a palliative care team or a physician or nurse who specialized or had a degree in palliative care in-or external to the facility) -No	Care staff

Answer categories marked with * have been recoded into one category.

[a] Italy, the Netherlands and Poland included facilities with onsite physicians and facilities with offsite general practitioners. In the other countries the treating physicians were offsite general practitioners.

[b] The following palliative care specialists were distinguished: *England*: palliative care team; *Belgium*: coordinating advising physician, reference nurse palliative care, palliative care team from facility, external palliative home care team; *the Netherlands*: physician with palliative care degree, palliative care specialist, palliative care specialist team; *Finland*: external consultant specialized in terminal care; *Poland*: palliative care physician, off-site palliative care nurse, off-site palliative care team i.e. hospice team; *Italy*: no predefined categories.

Table 2. Resident characteristics, facility characteristics and indicators of advance care planning included as independent variables

Variable	Question	Answer categories	Respondent
Resident characteristics			
Age	Age of resident?	Continuous (dichotomised to ≤85, >85)	Administrator
Sex	Sex of resident?	-Male -Female	Administrator
Length of stay (date of death – date of admission)	Date of facility admission? Date of death?	Continuous (dichotomised to <1 year, ≥1year	Administrator
Cancer diagnosis	Which of the following diseases was the resident suffering from at the time of death? -Cancer	-Yes -No	Care staff
Dementia	In your opinion, did the resident have dementia?	-Yes -No	Care staff
Facility characteristics			
LTCF type	Type of long term care facility?	-Onsite physicians, nurses and care assistants -Onsite nurses and care assistants, offsite physicians -Onsite care assistants, offsite nurses and physicians	Administrator
No. FTE nursing staff / No. occupied beds	Level of staffing (per function group). Total number of occupied beds in the facility on the date of completion.	Continuous (dichotomised at mean ≤5.25, >5.25)	Administrator
Specific written guidelines regarding palliative care	Does the facility have specific written guidelines with regard to providing palliative care?	-Yes -No* -Don't know*	Administrator
Multidisciplinary meetings	Is there a regular multidisciplinary meeting (with at least a physician and a nurse) to review treatment and care plans organized in your facility?	-Yes -No	Administrator

Table 2 (continued). Resident characteristics, facility characteristics and indicators of advance care planning included as independent variables

Variable	Question	Answer categories	Respondent
Case manager for residents with palliative care needs	Does your facility offer residents in need of palliative care an assigned contact person (e.g. care manager, case manager or key worker) who maintains a regular contact with the resident and his or her relatives?	-Yes, for all residents* -Yes, for most residents* -Yes, for some residents* -No, never	Administrator
Advance care planning			
Resident was capable of expressing his or her wishes at the time of admission	Was the resident capable of expressing his or her wishes at the time of admission?	-Yes -Partly -No	Care staff
Resident expressed specific preferences about a medical treatment he/she did not want during the last phase of life	Did the resident ever express specific preferences about a medical treatment he or she did or did not want during the last phase of life?	-Yes -No* -Don't know*	Care staff
Resident gave power to a third party	Did the resident, in a prior living will, give a power to a third party to take decisions for him or her in case he or she would be no longer competent to do so?	-Yes -No	Care staff
Spoke with the resident about medical treatments or about the preferred course of care	Did you ever speak with the resident about medical treatments or about the preferred course of care?	-Yes, only once* -Yes, several times* -No	Care staff
A contact person was mentioned in the resident's records	Was a contact person mentioned in the resident's records, which you were able to consult when taking decisions about the end of life in case the resident would be unable to do so?	-Yes -No	Care staff

Answer categories marked with * have been recoded into one category.

Analyses

Descriptive statistics were reported for residents characteristics and palliative care provision.

To account for clustering of data in facilities, Generalized Estimating Equations (GEE) with an exchangeable correlation structure was used for all analyses. Differences between countries were analysed using dummy variables of country as the independent variable and aspects of palliative care as dependent variables, these analyses were adjusted for resident characteristics.

To analyse which factors were associated with receiving palliative care and timing of palliative care, first univariable analyses were conducted. Next all factors were included in the multivariable GEE models and manual stepwise backward selection identified the factors most strongly associated (p-value <.05) with receiving and timing of palliative care. These analyses were adjusted for country. An interaction term with country was added to each independent variable in the final model, to evaluate possible effect modification by country.

For dichotomous dependent variables (resident received palliative care, treating physician provided palliative care, palliative care specialist involved), logistic GEE analyses were applied and odds ratios (ORs) with 95% confidence intervals (CIs) were calculated. Because timing of initiating palliative care was not normally distributed and some cases had a value of 0, a natural log transformation (on the value + 1) was used in linear GEE analyses and the ratios of geometric means and 95% CIs were calculated.

Sensitivity analyses were conducted to investigate the effect of missing data, by using complete cases (shown in results) and multiple imputation of missing data (shown in Supplement). Missing data were imputed 10 times using the 'micemd' package[17] in R[18], to perform multiple imputation using chained equations for multilevel data. Variables in the imputation models included dependent and independent variables used in GEE analyses. Information on missing data is displayed in Appendix table 1.

An alpha level <0.05 was considered statistically significant and the analyses, except the multiple imputations, were performed with SPSS version 22.[19]

Results

In all countries, except Poland, the majority of residents were over 85 years of age and resided in the facility for a year or longer (see table 3). In each country the majority of residents were female and most had dementia, while less than a quarter of residents had cancer at the time of death.

Table 3. Resident characteristics of study sample (n=1298)

Resident characteristics N (%)[a]	**BE (n=281)**	**FI (n=262)**	**IT (n=193)**	**NL (n=220)**	**PL (n=258)**	**EN (n=84)**	**All countries (n=1298)**
Age (>85)	172 (65.2)	141 (54.2)	108 (56.0)	118 (59.3)	101 (39.6)	53 (72.6)	693 (55.7)
Sex (female)	166 (63.4)	166 (64.8)	131 (68.2)	136 (66.7)	161 (63.1)	62 (75.6)	822 (65.7)
Length of stay (≥1 year)	173 (66.8)	154 (60.9)	100 (54.1)	131 (65.8)	103 (40.1)	46 (58.2)	707 (57.4)
Cancer (yes)	43 (15.6)	41 (16.2)	33 (17.7)	42 (19.8)	29 (11.7)	18 (22.5)	206 (16.4)
Dementia (yes)	177 (63.0)	218 (83.2)	151 (78.2)	135 (61.9)	170 (66.4)	49 (59.8)	900 (69.7)

Generalized Estimating Equations were used, Belgium was the reference category in all analyses.
BE=Belgium, FI=Finland, IT=Italy, NL=the Netherlands, PL=Poland, EN=England
[a] Due to missing cases all countries do not add up to n=1298 (see Appendix table 1).

Staff indicated that the resident received palliative care in 737 of 1298 cases (56.8%). Based on their reports, the proportion of residents who received palliative care was 14.0% in Poland and 32.1% in Italy, while in the other countries this was over 70% and up to 77.9% in Belgium (see table 4). In crude and adjusted analyses, the results in Italy and Poland significantly differed from the other countries. In crude analysis the difference between Italy and Poland was also statistically significant.

Timing of initiating palliative care was indicated in 485 of these 737 cases and ranged from 0 to 410 days before death. The median number of days when palliative care was started, ranged from 6 in Italy to 14.5 in Poland. Crude and adjusted analyses showed that in Italy, Finland (median 7.0) and the Netherlands (median 7.0) palliative care started significantly later, compared to Belgium (median 11) and Poland. In the Netherlands timing was also significantly later than in England (median 8.50).

Care staff indicated whether the treating physician provided palliative care in 718 of 737 cases (97.4%) and this physician provided palliative care in the majority of cases. In crude and adjusted analyses the treating physician was involved significantly more often in the Netherlands (98.8%) compared to all other countries ($p<.001$), ranging

from 70.5% in Finland to 83.8% in Belgium. Finland also differed significantly from Belgium (p<.05).

In 656 out of 737 cases (89.0%) staff specified whether a palliative care specialist was involved in providing palliative care. Both crude and adjusted analysis showed that in Belgium and Poland staff indicated in significantly more cases that a palliative care specialist was involved (86.7% and 57% respectively), compared to Finland (2.8%), the Netherlands (8.1%) and England (25.9%). Significant differences were also found between England and both Finland and the Netherlands (p<.05) and between Belgium and Poland (p<.05). In Italy specialist palliative care was not available in long-term care.

Table 4. Palliative care provision in LTCFs and differences between countries

All residents in sample (n=1298)		**Residents who received palliative care (n=737)**		
Country	**Resident received palliative care** (yes)*	**Timing of initiating palliative care** (days before death)*[b]	**Treating physician provided palliative care** (yes)*	**Palliative care specialist involved in providing palliative care** (yes)*[c]
(N)	N(%)	Median (IQR), min-max	N(%)	N(%)
BE (281)	219 (77.9)	11.00 (7.00-30.00), 0-365	181 (83.8)	183 (86.7)
FI (262)	191 (72.9)	7.00 (3.50-15.00), 0-340	129 (70.5)	5 (2.8)
IT (193)	62 (32.1)	6.00 (4.25-7.75), 2-55	47 (77.0)	0 (0.0)
NL (220)	168 (76.4)	7.00 (3.00-14.00), 0.5-130	165 (98.8)	13 (8.1)
PL (258)	36 (14.0)	14.50 (7.00-52.5), 2-410	29 (82.9)	20 (57.1)
EN (84)	61 (72.6)	8.50 (4.75-28.5), 2-126	42 (75.0)	14 (25.9)

IQR=interquartile range. Generalized Estimating Equations were used.

BE=Belgium, FI=Finland, IT=Italy, NL=the Netherlands, PL=Poland, EN=England

*Overall p-values in crude and adjusted analyses were <.001

a: Analyses were adjusted for: age >85, gender, length of stay ≥1 year, cancer diagnosis and dementia.

b: Dependent variable: LN (timing of palliative care in days before death+1).

c: Italy was left out of GEE analysis because analyses did not converge due to the empty cell; all 17 Italian cases with a valid value indicated no involvement of specialist.

Table 5 shows associations between receiving palliative care and resident, facility and advance care planning factors. In univariable analyses cancer, dementia, type of LTCF, an assigned case manager and a contact person mentioned in the resident's record showed significant associations with residents receiving palliative care according to care staff. The final multivariable model showed staff were more likely to indicate a resident received palliative care, when the resident had cancer (OR 1.928 [1.243-2.993]), dementia (OR 1.429 [1.093-1.869]), or a contact person mentioned in their record (OR 2.401 [95% CI 1.573-3.665]), compared to residents without. A significant interaction with country was observed for cancer and dementia. The association with cancer was stronger in Poland and England (OR 6.820 [95% CI 2.832-16.421] and OR 6.867 [95% CI 1.488-31.700] respectively) and the association with dementia was stronger in Belgium (OR 2.502 [95% CI 1.572-3.983]), compared to the other countries.

Table 6 shows associations between timing of initiating palliative care and resident, facility and advance care planning factors. In univariable analyses the variables facility type and staff speaking with the resident about their preferences for care, were significantly related to the timing of initiating palliative care as indicated by care staff. The multivariable model showed that palliative care started significantly earlier for residents with whom care staff had spoken about treatments or the preferred course of care, compared to residents who didn't discuss this with staff (geometric mean ratio 1.357 [95% CI 1.084-1.700]). No interaction with country was observed.

Sensitivity analyses showed that differences between countries were little affected by missing data imputation (see Appendix table 2). Furthermore ORs and CIs of variables associated with receiving palliative care were largely comparable between imputed data and complete cases (see Appendix table 3). However, the imputed model included availability of a case manager and country showed no interaction with dementia. Regarding timing of palliative care, only the difference between the Netherlands and Belgium was statistically significant (see Appendix table 2) and the relation with care staff having spoken with the resident was less strong and below significance level in imputed data (see Appendix table 4).

Table 5. Factors associated with receiving palliative care

	Received palliative care		Univariable OR (95% CI)[a]	p-value	Multivariable OR (95% CI)[b]	p-value
	Yes (n=737)	**No (n=561)**				
RESIDENT CHARACTERISTICS						
Age, *>85*	414 (59.8)	279 (50.5)	1.04 (.80-1.35)	.787		
Sex, *female*	459 (65.9)	363 (65.4)	1.04 (.80-1.34)	.785		
Length of stay, *≥1year*	420 (60.8)	287 (53.0)	.92 (.67-1.25)	.577		
Cancer diagnosis, *yes*	142 (19.7)	64 (12.0)	1.71 (1.14-2.57)	.009	1.93 (1.24-2.99)	.003
Dementia, *yes*	519 (70.8)	381 (68.2)	1.33 (1.04-1.70)	.026	1.43 (1.09-1.87)	.009
FACILITY CHARACTERISTICS						
LTCF type						
Onsite physicians, nurses and care assistants	120 (16.9)	189 (34.3)	Reference			
Onsite nurses and care assistants, offsite physicians	569 (80.1)	346 (62.8)	.93 (.52-1.67)	.807		
Onsite care assistants, offsite nurses and physicians	21 (3.0)	16 (2.9)	.23 (.06-.89)	.034		
No. FTE nusing staff / 10. occupied beds, *>5.25*	347 (50.7)	180 (33.6)	1.22 (.72-2.06)	.458		
Specific written guidelines regarding palliative care, *yes*	471 (69.1)	214 (39.4)	1.12 (.73-1.74)	.605		
Case manager for residents with palliative care needs, *yes*	570 (81.8)	327 (59.6)	1.56 (1.01-2.40)	.044		
Multidisciplinary meetings, *yes*	548 (78.3)	408 (74.9)	1.16 (.68-1.96)	.592		
ADVANCE CARE PLANNING						
Resident was capable of expressing his or her wishes at the time of admission						
Yes	294 (40.4)	175 (31.4)	.77 (.54-1.10)	.147		
Partly	240 (33.0)	179 (32.1)	.90 (.63-1.30)	.583		
No	193 (26.5)	203 (36.4)	Reference			

Resident expressed specific preferences about a medical treatment he/she did not want during the last phase of life, *yes*	214 (29.4)	70 (12.5)	1.29 (.88-1.90)	.186		
Resident gave power to a third party, *yes*	207 (29.2)	148 (27.9)	1.32 (.98-1.79)	.073		
Spoke with the resident about medical treatments or about the preferred course of care, *yes*	229 (31.8)	98 (18.1)	1.24 (.89-1.72)	.211		
A contact person was indicated in the resident's records, *yes*	675 (92.8)	417 (79.4)	2.53 (1.73-3.71)	.000	2.40 (1.57-3.67)	.000

OR= Odds Ratio, CI= Confidence Interval.

Logistic GEE analyses. Dependent variable: According to you, did the resident receive palliative care at any time? (0 – no, 1- yes)

a: Association between dependent variable and independent variables separately, adjusted for country.

b: Association between dependent variable and independent variables in model built by backward selection, adjusted for country.

Table 6. Factors associated with timing of initiating palliative care

			Timing of initiating palliative care (in days before death) Median (IQR)	Univariable Ratio (95% CI) [a]	p-value	Multivariable Ratio (95% CI) [b]	p-value
RESIDENT CHARACTERISTICS							
Age,	*≤85*		10.00 (4.00-20.00)	Reference			
	>85		7.00 (4.00-20.00)	.95 (.78-1.15)	.590		
Sex,	*Male*		8.00 (4.00-28.50)	Reference			
	Female		8.00 (4.00-15.00)	.95 (.78-1.16)	.631		
Length of stay,	*<1 year*		7.00 (4.00-14.00)	Reference			
	≥1year		10.00 (5.00-28.00)	1.21 (.99-1.47)	.056		
Cancer diagnosis,	*no*		7.50 (4.00-15.75)	Reference			
	yes		10.50 (4.00-29.50)	1.18 (.94-1.47)	.146		
Dementia,	*no*		10.00 (5.00-27.00)	Reference			
	yes		7.00 (4.00-16.00)	.83 (.67-1.03)	.085		
FACILITY CHARACTERISTICS							
LTCF type,	*Onsite physicians, nurses and care assistants*		7.00 (3.00-14.00)	Reference			
	Onsite nurses and care assistants, offsite physicians		10.00 (5.00-21.00)	1.49 (1.02-2.18)	.038		
	Onsite care assistants, offsite nurses and physicians		7.00 (5.00-28.00)	1.32 (.59-2.95)	.501		
No. FTE nusing staff / 10. occupied beds,		*≤5.25*	10.00 (7.00-30.00)	Reference			
		>5.25	7.00 (3.00-14.00)	.88 (.68-1.14)	.334		
Specific written guidelines regarding palliative care,		*no + don't know*	7.00 (3.25-14.00)	Reference			
		yes	10.00 (6.00-27.00)	1.27 (.98-1.66)	.070		

Case manager for residents with palliative care needs, *no*		10.00 (6.00-19.00)	Reference			
	yes	8.00 (4.00-20.00)	.87 (.67-1.13)	.303		
Multidisciplinary meetings,	*no*	7.00 (4.00-14.00)	Reference			
	yes	10.00 (4.00-21.00)	1.29 (.97-1.71)	.085		
ADVANCE CARE PLANNING						
Resident was capable of expressing his or her wishes at the time of admission,	*No*	7.00 (4.00-15.00)	Reference			
	Partly	10.00 (4.00-16.00)	1.22 (.97-1.54)	.096		
	Yes	10.00 (4.00-28.00)	1.19 (.95-1.48)	.128		
Resident expressed specific preferences about a medical treatment he/she did not want during the last phase of life,	*no + don't know*	8.00 (4.00-15.00)	Reference			
	yes	10.00 (4.00-27.00)	1.05 (.83-1.33)	.677		
Resident gave power to a third party,	*no*	7.00 (4.00-15.00)	Reference			
	yes	11.00 (6.00-30.00)	1.25 (.97-1.60)	.081		
Spoke with the resident about medical treatments or about the preferred course of care,	*no*	7.00 (4.00-14.00)	Reference			
	yes	14.00 (6.00-30.00)	1.36 (1.08-1.70)	.008	1.36 (1.08-1.70)	.008
A contact person was indicated in the resident's records,	*no*	7.00 (4.00-12.00)	Reference			
	yes	9.00 (4.00-20.00)	1.27 (.93-1.74)	.132		

IQR= Interquartile Range, CI= Confidence Interval. Ratio=Ratio of geometric means.

Linear GEE analyses. Dependent variable: LN (no. of days before death when palliative care was started +1).

a: Association between dependent variable and independent variables separately, adjusted for country.

b: Association between dependent variable and independent variables in model built by backward selection, adjusted for country.

Discussion

This study showed that, except in Italy and Poland, care staff indicated in a majority of cases that the resident received palliative care. In most of these cases the treating physician (GP/physician employed in facility) provided palliative care and in Poland and Belgium a palliative care specialist was often involved. Palliative care typically started a maximum of 2 weeks before death (median). Staff more often indicated that residents received palliative care if they had cancer, dementia, or a contact person in their record. Care staff stated a significantly earlier starting time of palliative care when they had spoken with the resident about treatment or preferred care.

Palliative care provision in LTCFs

The findings regarding the proportion of residents who received palliative care and who was involved in providing palliative care, can be related to palliative care policy and guidelines, initiatives aimed at developing palliative care and organization of (palliative) care in long-term care facilities in the participating countries. In Belgium, England and the Netherlands national policy, care standards or guidelines are instated regarding palliative care provision in long-term care facilities and formal initiatives have been established to develop palliative care in this setting. In Finland such palliative care policies have not been identified, but programmes to provide palliative care education to long-term care facility staff have started. In Poland and Italy neither palliative care policies nor initiatives to develop palliative care in long-term care facilities have been identified.[20] Therefore, palliative care was possibly not available for many residents in Poland and Italy, or care staff did not distinguish care they provided themselves as palliative care but as routine long-term care, which could explain why staff in Poland and Italy reported that only a small minority of residents received palliative care. Additionally, in Italy palliative care provision could have also been hampered by closely involved relatives[21] who may have had an incorrect perception of palliative care.[22] In these cases, even when care professionals wanted to initiate palliative care, relatives could have defied these efforts because they were unsure of what this would mean in terms of care for the resident.

According to literature, there are three levels of palliative care provision: a palliative care approach (palliative care provided by care staff); general palliative care (provided by primary care professionals such as the treating physician); and palliative care provided by specialised services, when complex problems are not sufficiently covered by the other treatment options.[23] In this study the question whether residents received palliative care, included any level of palliative care and we further distinguished general and specialist palliative care.

Concerning the involvement of the treating physician, i.e. general palliative care, no distinct difference was seen between countries where the treating physician included both onsite and offsite physicians (Poland, Italy and the Netherlands) and countries where all treating physicians were offsite (Finland, Belgium, England). The type of long-term care facility was also not associated with whether or not residents received palliative care. Thus treating physicians often provided palliative care, regardless of their employment in- or outside the facility. However, Dutch staff reported involvement of the treating physician not only in the majority of cases, but in almost all cases. This is probably due to Dutch policy in which palliative care is considered mainly as generalist care, while this view is not expressed in policies in the other countries.[24, 25]

In Belgium palliative care reference nurses –who followed specialized palliative care training- are employed in long-term care facilities in Belgium, while in the other countries the palliative care specialists considered in this study are external to the facility.[20, 26] This explains the high degree of palliative care specialist involvement in Belgium, since specialist palliative care is more easily available in the actual facilities. And while in Poland few residents received palliative care, a palliative care specialist was involved in over half of those residents, which is likely a result of the reimbursement system of care in long-term care facilities. In Poland residents in facilities with onsite physicians are reimbursed only for care labelled as long-term care, while residents treated by offsite GPs, are reimbursed for specialist palliative care only in certain diagnoses, such as cancer or cardiomyopathy.[20, 26] Thus many residents are excluded from receiving care labelled as palliative care, while specialist palliative care will have frequently been provided to those who did receive palliative care.

Timing of initiating palliative care

In all countries the median time of initiating palliative care did not exceed 2 weeks before death, therefore for a substantial proportion of residents palliative care was probably started when staff recognized their impending death. This late initiation of palliative care might not only be an issue in European long-term care facilities, since referral to specialist palliative care services also occurred quite close to death in other populations: on average 29 days before death in long-term care residents in the U.S.[27] and 15-30 days before death in general practice populations in Belgium, the Netherlands, Italy and Spain.[9] Furthermore care staff possibly only labelled care during the last days of life as palliative care and may have regarded palliative care as terminal care.[23] Compared to late palliative care, earlier initiated palliative care has shown more benefits and greater effect on outcomes related to the end of life, such as hospitalization rates,[28-30] quality of life and symptom severity.[31] While the importance of early palliative care is extensively noted in oncology care,[32-35] our study indicates that such notion is not yet thoroughly established in long-term care facilities.

Factors related to receiving palliative care and timing of initiating palliative care

Involvement of relatives could play a role in initiating palliative care, as staff more often reported that residents received palliative care, when a contact person was mentioned in their record. Previous research found that families of nursing home residents stated to often feel the need to advocate for their dying relative, especially when they had concerns regarding the quality of provided care.[36] Similarly, family carers of older people in hospital play an important role in identifying care needs and often advocate on their relative's behalf.[37] However, since this study is cross-sectional, reverse causality is possible and a contact person could also be noted more often once palliative care was started, for instance the designated relative to notify when the resident's condition worsens.

Staff were more likely to indicate residents received palliative care when they had cancer or dementia. In other studies patients with cancer were indeed more likely to receive palliative care,[9-12 38] probably because their trajectory of decline and care needs are more predictable than in patients with non-malignant illnesses.[39] In Poland and England cancer and palliative care were strongly associated, perhaps because in Poland palliative care is reimbursed for those with cancer[26] and in England many palliative care services originated in cancer care.[40] While palliative care needs in people with dementia have often been under-recognized,[41, 42] recent efforts to gain more attention for palliative care in dementia[43] could be reflected in the current study. In Belgium the relationship between dementia and palliative care was stronger than in the other countries, which is consistent with findings in Belgian general practices where patients with dementia more often had a palliative treatment goal than patients without dementia.[44]

Advance care planning seems related to an earlier start of palliative care, as staff indicated a significantly earlier initiation of palliative care when they spoke with the resident about their care preferences. Advance care planning increases compliance with patient's wishes for care[45, 46] and residents may have preferred palliative care, which was therefore started earlier. The relation between the initiation of palliative care and specific preferences stated by long-term care residents deserves further investigation in future research. Advance care planning could be considered integral to palliative care[47-49] and one could argue that staff in this study regarded discussing care preferences as providing palliative care. However, as it aims to discuss preferences for future care in case one becomes unable to make decisions,[50] it may start early in one's disease trajectory, opposed to the overall late initiation of palliative care in the current study.

Few of the factors included in this study showed a relation with palliative care provision in long-term care, indicating other factors could play a role. Organizational culture in facilities, including teamwork, communication and leadership, is reflected in the care delivered to residents.[51, 52] Future studies could investigate the influence of organizational culture on palliative care provision.

Strengths and limitations

This is the first study systematically describing and comparing palliative care provision in long-term care facilities in Europe, using representative samples of facilities. The retrospective design is the most appropriate to make population-based estimates of provided palliative care, as this is more inclusive than a prospective design and ensured inclusion of all eligible cases.[53] Furthermore, since sensitivity analyses showed mostly similar results, the influence of missing data was rather small. Therefore the data on provided care could be considered representative of the whole sample and could inform future palliative care developments in these countries. However multiple imputation did show a weaker relation between timing of initiating palliative care and an advance care planning conversation with the resident, indicating that this result should be interpreted with caution.

The most important limitation of this study is lack of a definition of palliative care in the questionnaire filled out by staff. We cannot be certain how staff interpreted palliative care, since research found the concept of palliative care not to be consistently interpreted by nursing home managers[54] and care providers,[55] and its definition seemed to differ between languages.[56] Therefore the interpretation of palliative care could have differed among staff and between countries. However, a cross-cultural translation of questionnaires was conducted and tested in a pilot-study in each country, making it more likely that we actually measured palliative care provision. Also in the PACE project questionnaires on care for deceased residents and on palliative care knowledge were distributed to care staff simultaneously,[15, 57] thus providing a definition of palliative care could have contaminated results on palliative care knowledge. Also, while recall bias cannot be excluded, it was limited because nurses could look up information in resident's files and consult other staff members to verify their responses.

Conclusions

The late initiation of palliative care (especially when advance care planning is lacking) and palliative care for residents without cancer, dementia or closely involved relatives deserve attention in all countries. Diversity in palliative care organization probably results in different levels of its development, with the lowest in Poland and Italy.

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Appendix

Appendix table 1. Display of missing data

		Cases with missing data (%)	
Independent variables	**N**	**(%) of total sample (n=1298)**	**(%) of subgroup sample who received palliative care (n=737)**
Age	54	(4.2)	(7.3)
Sex	47	(3.6)	(6.4)
Length of stay	66	(5.1)	(9.0)
Cancer diagnosis	43	(3.3)	(5.8)
Dementia	6	(0.5)	(0.8)
LTCF type	0	(0)	(0)
No. FTE care staff / No. occupied beds	78	(6.0)	(10.6)
Specific written guidelines regarding palliative care	73	(5.6)	(9.9)
Case manager for residents with palliative care needs	52	(4.0)	(7.1)
Multidisciplinary meetings	53	(4.1)	(7.2)
Resident was capable of expressing his or her wishes at the time of admission	14	(1.1)	(1.9)
Resident expressed specific preferences about a medical treatment he/she did not want during the last phase of life	11	(0.8)	(1.5)
Resident gave power to a third party	60	(4.6)	(8.1)
Spoke with the resident about medical treatments or about the preferred course of care	35	(2.7)	(4.7)
A contact person was mentioned in the resident's records	46	(3.5)	(6.2)
Country	0	(0)	(0)
Dependent variables			
Resident received palliative care	0	(0)	-
Timing of initiating palliative care	252	-	(34.2)
Treating physician involvement in providing palliative care	19	-	(2.6)
Involvement of palliative care expert in providing palliative care	98	-	(13.3)

Appendix table 2. Palliative care provision in LTCFs and differences between countries, using multiple imputed datasets

All Residents in sample n=1298		**Residents who received palliative care (n=737)**		
Country	**Received palliative care** (yes)	**Timing of initiating palliative care** (days before death)	**Treating physician provided palliative care** (yes)	**A palliative care expert was involved in the provision of palliative care** (yes)
(N)	N(%)	Median (IQR)[b]	N(%)	N(%)
BE (281)	219 (77.9)	10.30 (6.10-28.80)	183 (83.6)	186 (84.9)
FI (262)	191 (72.9)	7.50 (4.00-17.80)	136 (71.2)	11 (5.8)
IT (193)	62 (32.1)	6.80 (4.45-14.63)	48 (77.4)	17 (27.4)
NL (220)	168 (76.4)	7.00 (3.15-14.00)	166 (98.8)	16 (9.5)
PL (258)	36 (14.0)	12.05 (6.93-38.30)	30 (83.3)	20 (55.6)
EN (84)	61 (72.6)	8.40 (4.30-24.60)	46 (75.4)	16 (26.2)
Overall p-values				
Crude analysis[a]	<.001	.004	<.001	<.001
Adjusted analysis	<.001	.002	<.001	<.001

IQR=interquartile range. Generalized Estimating Equations were used.

a: Median p-value was used as a measure of the pooled overall p-value [158].

b: Pooled median and IQR values were calculated as the mean of median and IQR in each imputed dataset.

Appendix table 3. Factors associated with receiving palliative care, using multiple imputed datasets

	Received palliative care Yes (n=737)	No (n=561)	Univariable OR (95% CI)[a]	p-value	Multivariable OR (95% CI)[b]	p-value	OR for different countries (95%CI) [p-value][c]	interaction term with country, p-value
RESIDENT CHARACTERISTICS								
Age, *>85*	438 (59.4)	284 (50.6)	1.02 (0.78-1.32)	.891				
Sex, *female*	486 (65.9)	367 (65.4)	1.03 (0.80-1.33)	.805				
Length of stay, *≥1year*	446 (60.5)	299 (53.3)	0.90 (0.66-1.22)	.498				
Cancer diagnosis, *yes*	145 (19.7)	68 (12.1)	1.67 (1.12-2.49)	.012	1.82 (1.21-2.73)	.004	PL: 5.71 (2.34-13.90) [<.001] EN: 3.53 (1.12-11.15) [.032] BE: 1.26 (0.56-2.83) [.580] NL: 1.38 (0.58-3.27) [.460] FI: 1.40 (0.64-3.03) [.399] IT: 1.41 (0.71-2.80) [.325]	.061
Dementia, *yes*	522 (70.8)	382 (68.1)	1.33 (1.04-1.71)	.023	1.42 (1.08-1.85)	.011	-	.171

Appendix table 3 (continued). Factors associated with receiving palliative care, using multiple imputed datasets

	Received palliative care							
	Yes (n=737)	**No (n=561)**	**Univariable OR (95% CI)[a]**	**p-value**	**Multivariable OR (95% CI)[b]**	**p-value**	**OR for different countries (95%CI) [p-value][c]**	**interaction term with country, p-value**
FACILITY CHARACTERISTICS								
LTCF type								
LTCF on site day and night GPs and nurses	121 (16.4)	189 (33.7)	Reference					
LTCF onsite nurses offsite GPs	595 (80.7)	356 (63.5)	0.95 (0.53-1.69)	.861				
LTCF offsite nurses and GPs	21 (2.8)	16 (2.9)	0.23 (0.06-0.91)	.036				
No. care staff / 10. occupied beds, *>5.25*	370 (50.2)	190 (33.9)	1.22 (0.75-1.98)	.429				
Specific written guidelines regarding palliative care, *yes*	500 (67.8)	226 (40.3)	1.02 (0.66-1.58)	.939				
Case manager/assigned contact person, *yes*	599 (81.3)	336 (59.9)	1.52 (1.00-2.31)	.049	1.57 (1.02-2.40)	.038	-	.248
Multidisciplinary meetings, *yes*	576 (78.2)	420 (74.9)	1.12 (0.68-1.83)	.661				
ADVANCE CARE PLANNING								
Resident was capable of expressing his or her wishes at the time of admission								
Yes	298 (40.4)	177 (31.6)	0.78 (0.55-1.11)	.170				
Partly	243 (33.0)	180 (32.1)	0.92 (0.64-1.31)	.633				
No	196 (26.6)	204 (36.4)	Reference					
Resident expressed specific preferences about a medical treatment	216 (29.3)	71 (12.7)	1.29 (0.88-1.88)	.194				

he/she did not want during the last phase of life, *yes*								
Resident gave power to a third party, *yes*	215 (29.2)	158 (28.2)	1.31 (0.97-1.78)	.077				
Spoke with the resident about medical treatments or about the preferred course of care, *yes*	233 (31.6)	103 (18.4)	1.25 (0.90-1.75)	.186				
A contact person was mentioned in the resident's records, *yes*	683 (92.7)	449 (80.0)	2.29 (1.58-3.31)	<.001	2.28 (1.54-3.37)	<.001	-	.601

OR= Odds Ratio, CI= Confidence Interval.

Logistic GEE analyses. Dependent variable: According to you, did the resident receive palliative care at any time? (0 – no, 1- yes).

Median p-value was used as a measure of the pooled overall p-values [158].

a: Association between dependent variable and independent variables separately, adjusted for country.

b: Association between dependent variable and independent variables in model built by backward selection, adjusted for country.

c: Association between dependent and independent variables in backwards model, including interaction term between country and independent variables identified in backward selection.

Appendix table 4. Factors associated with timing of initiating palliative care, using multiple imputed datasets

		Timing of initiating palliative care (days before death) Median (IQR)	Univariable Ratio (95% CI) [a]	p-value	Multivariable Ratio (95% CI) [b]	p-value	Multivariable ratio for different countries Ratio (95%CI) [p-value][c]	Interaction term with country, p-value
RESIDENT CHARACTERISTICS								
Age,	*≤85*	9.90 (4.20-19.45)	Reference					
	>85	7.70 (4.10-18.63)	0.96 (0.80-1.15)	.628				
Sex,	*male*	8.40 (4.20-24.58)	Reference					
	female	8.30 (4.30-16.90)	0.95 (0.80-1.13)	.547				
Length of stay,	*<1 year*	7.30 (4.03-15.18)	Reference					
	≥1year	9.75 (4.60-23.38)	1.15 (0.95-1.38)	.144				
Cancer diagnosis,	*no*	7.75 (4.20-17.88)	Reference					
	yes	9.90 (4.13-23.28)	1.11 (0.91-1.36)	.298				
Dementia,	*no*	9.95 (4.65-23.88)	Reference					
	yes	7.30 (4.10-18.05)	0.89 (0.72-1.10)	.265				
FACILITY CHARACTERISTICS								
LTCF type								
	Onsite physicians, nurses and care assistants	7.00 (3.20-14.00)	Reference					
	Onsite nurses and care assistants, offsite physicians	9.10 (4.60-20.90)	1.28 (0.93-1.77)	.131				
	Onsite care assistants, offsite nurses and physicians	8.00 (4.80-24.65)	1.26 (0.60-2.65)	.543				

No. FTE nusing staff / 10. occupied beds, *≤5.25*		10.00 (5.50-26.53)	Reference					
	>5.25	7.00 (3.90-14.70)	0.86 (0.67-1.11)	.245				
Specific written guidelines regarding palliative care,	*no + don't know*	7.00 (3.93-14.50)	Reference					
	yes	9.90 (5.00-22.10)	1.14 (0.88-1.47)	.332				
Case manager for residents with palliative care needs,	*no*	8.80 (5.18-20.48)	Reference					
	yes	8.15 (4.10-18.80)	0.93 (0.70-1.24)	.626				
Multidisciplinary meetings,	*no*	7.00 (3.93-15.35)	Reference					
	yes	9.80 (4.45-20.48)	1.22 (0.92-1.61)	.160				
ADVANCE CARE PLANNING								
Resident was capable of expressing his or her wishes at the time of admission,	*No*	7.00 (4.20-16.55)	Reference					
	Partly	9.55 (4.00-18.40)	1.16 (0.93-1.44)	.199				
	Yes	9.55 (4.28-24.90)	1.16 (0.93-1.44)	.196				
Resident expressed specific preferences about a medical treatment he/she did not want during the last phase of life,	*no + don't know*	7.60 (4.30-17.60)	Reference					
	yes	9.40 (4.50-22.65)	1.05 (0.87-1.26)	.625				
Resident gave power to a third party,	*no*	7.40 (4.00-17.08)	Reference					
	yes	10.20 (5.83-27.28)	1.17 (0.94-1.46)	.154				
Spoke with the resident about medical treatments or about the preferred course of care,	*no*	7.10 (4.00-15.60)	Reference					
	yes	10.50 (5.68-29.73)	1.24 (0.99-1.54)	.060	1.24 (0.99-1.54)	.060	-	0.154

Appendix table 4 (continued). Factors associated with timing of initiating palliative care, using multiple imputed datasets

		Timing of initiating palliative care (days before death) Median (IQR)	Univariable Ratio (95% CI) [a]	p-value	Multivariable Ratio (95% CI) [b]	p-value	Multivariable ratio for different countries Ratio (95%CI) [p-value] [c]	Interaction term with country, p-value
A contact person was mentioned in the resident's records,	*no*	6.95 (3.93-13.70)	Reference					
	yes	8.90 (4.40-19.85)	1.22 (0.89-1.66)	.215				

IQR= Interquartile Range, CI= Confidence Interval. Ratio=Ratio of geometric means.

Linear GEE analyses. Dependent variable: LN (no. of days before death when palliative care was started +1).

Pooled median and IQR values were calculated as the mean of median and IQR in each imputed dataset. Median p-value was used as a measure of the pooled overall p-values[158].

a: Association between dependent variable and independent variables separately, adjusted for country.

b: Association between dependent variable and independent variables in model built by backward selection, adjusted for country.

c: Association between dependent and independent variables in backwards model, including interaction term between country and independent variables identified in backward selection.